

Journal article

Participatory prognostics in Germany

Developing citizen scenarios for the relationship between biomedicine and the economy in 2014

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2005

Abstract: The rapid development of biomedicine demands a trustworthy, proactive regulatory regime that is able to manage progress with genuine regard for ethical, social and legal concerns. With its recent past of eugenics and euthanasia, Germany is particularly concerned with setting up a fair and transparent approach, able to respond quickly to scientific developments as well as societal concerns. This article reports on the development, implementation and evaluation of a citizen scenario workshop as a tool of participatory prognostics, integrating elements from participatory technology assessment and forecasting. In 7 days of highly structured work and expert support, 24 German participants developed four scenarios on “The Relationship of Biomedicine and the Economy in the Year 2014.” Results and evaluation both show that the process (1) leads to scenarios that provide a useful perspective beyond expert opinion; (2) enriches the public and political discourse; and (3) offers a social learning opportunity appreciated by nonprofessionals and experts alike. We are confident in recommending this technique as a useful addition to existing foresight and horizon scanning activities.

Keywords: Germany, biomedicine, economy

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Title:

“Participatory prognostics in Germany – developing citizen scenarios for the relationship between biomedicine and the economy in 2014”

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Abstract

The rapid development of biomedicine demands a trustworthy, proactive regulatory regime that is able to manage progress with genuine regard for ethical, social and legal concerns. With its recent past of eugenics and euthanasia, Germany is particularly concerned with setting up a fair and transparent approach, able to respond quickly to scientific developments as well as societal concerns.

This paper reports on the development, implementation and evaluation of a citizen scenario workshop as a tool of participatory prognostics, integrating elements from participatory technology assessment and forecasting. In seven days of highly structured work and expert support, 24 German participants developed four scenarios on “The relationship of biomedicine and the economy in the year 2014”.

Results and evaluation both show that the process (1) leads to scenarios that provide a useful perspective beyond expert opinion; (2) enriches the public and political discourse and (3) offers a social learning opportunity appreciated by non-professionals and experts alike. We are confident in recommending this technique as a useful addition to existing foresight and horizon scanning activities.

Introduction

Biomedicine in Germany

Human genomics has advanced over recent decades to become one of the fastest growing areas in elementary research as well as clinical and industrial application¹⁻³. Symbolic scientific milestones such as the mapping of the entire human genome⁴ or the ongoing discovery of the ever-changing potential of stem cells⁵ have created a fast-moving, excited societal discourse around future prospects particularly in the areas of genetic diagnostics and regenerative medicine.

At the same time, critical and cautious voices have grown louder pointing towards the ethical problematic of embryo research, religious conflicts in pluralistic societies⁶⁻⁸ or questioning the desirability of biomedical research altogether⁹.

Particularly in Germany, those who take a rather sceptical stance toward the latest developments in molecular medicine and biology have a strong position in the political-legal and public discourse for a number of reasons, including the country's recent past with its record of eugenics and euthanasia¹⁰.

The dilemma of control

In this volatile environment, anticipating future developments of innovative technologies is extremely difficult yet important in order to retain a proactive ability to control and foster positive development of research and application, assess potential impacts and limit unwanted consequences while still reaping the benefits taking into account justified social, ethical and legal concerns¹¹.

The complex and paradoxical relationship between technological evolution and its societal control is well known as the Collingridge-Dilemma. In its early stages, assessing the development and impact of a new technology tends to suffer from fundamental uncertainties and ignorance at a scientific-technical level rendering regulation and management difficult. The technology's societal penetration on the other hand, its embeddedness in societal discourse and practices, is low. *In principle*, this enables flexible

regulation without excessive resource (cost) implications. Scientific technical uncertainty decreases as the technology itself and its various applications become better understood. *In principle*, this improves the opportunity for effective and efficient regulation. Yet societal penetration progresses in parallel, increasing the cost of regulation and, *in reality*, often hindering the implementation of effective regimes¹².

In trying to deal with this dilemma, managers and regulators traditionally have a number of options:

- (1) "Sit and wait": Carefully monitor developments until the baseline data is sufficient to warrant particular action
- (2) "Prognostics": Use of expert judgement-based forecasting approaches such as Delphi^{13,14}
- (3) "Integrative exploration": contextual and integrative exploration of a wide range of impacts using a broad knowledge and experience base; focus on ripple effects, possible interactions, wild cards, etc.¹⁵⁻¹⁷

For biomedical developments that demand proactive political and regulatory action, "sit and wait" is often an unrealistic option not least due to legal constraints based on, e.g. a duty of care. Hence the following sections will argue the case for "integrative exploration" as an option linking the forward looking approach of prognostics with participatory and discursive techniques more akin to participatory technology assessment.

Technology assessment and political culture

In the US and Europe, participatory techniques have become increasingly desirable in political decision-making over recent years and continue to do so¹⁸⁻²⁰. Germany, however, has relied for a long time on elections as a sufficient means of public representation in political decision-making and is only now beginning to move towards a wider set of methods for public engagement. Compared to some of its European neighbours such as Switzerland, with a strong tradition of direct democracy (referenda are unconstitutional in Germany at federal level), or Denmark with its history of participatory technology

assessment, Germany is a long way away from integrating participatory techniques into its political culture.

Nevertheless, in the context of genomics, the high profile Enquête Commission “Law and Ethics in Modern Medicine” of the Deutsche Bundestag (House of Representatives) argued in its final report²¹ that parliament should support

- (1) the democratic public discussion about ethical, legal and social questions in modern medicine;
- (2) specifically the public discourse processes that are based on the active involvement of citizens and
- (3) policy advice panels that involve the public in an appropriate and especially dialogic format.

A range of techniques is available to involve the public in risk and technology assessments²²⁻²⁴. Participatory technology assessments, for example, employ focus groups, consensus conferences or citizens’ juries and typically aim to elicit participants’ attitudes, beliefs and values within a certain context in an attempt to arrive at a more comprehensive knowledge base than would be possible using scientific-technical knowledge only²⁵⁻²⁹. They are typically designed as decision support tools for an existing decision problem. Rarely do they deal explicitly with possible future developments.

Participatory prognostics

Creating and evaluating possible future developments has been the role of forecasting and prognostics which have traditionally relied on expert- or stakeholder-based processes. Particularly in highly complex areas such as economics and medical science, predictions, forecasts and best estimates have been and continue to be developed predominantly by those who have a good grasp of the scientific-technical issues as a matter of their profession or long-term involvement in a particular field.

In this context, a tool that has received increasing attention over recent years is the scenario method^{24,30-34}. “Scenario analysis is an interactive process engaging a group in a

process of identifying key issues, creating and exploring scenarios in order to learn about the external environment and/or integrating the insights into the decision-making of [an] organisation.”³⁵

The scenario method was initially conceptualised as a tool to support strategic management^{36,37}. Typically, scenario building starts with the current status quo and tries to identify driving forces that may influence future developments. Scenarios can be built using different assumptions regarding the direction in which these forces may act, and a consistent combination of these assumptions for different driving forces³⁸. Oftentimes, these scenarios enable the participants to identify possible positive and negative consequences for a particular field of reference and to recommend strategic action in an attempt to maximise opportunities and avoid or minimise risks.

Besides their use in current business practice, the method is an integral part of technology assessment³³, as part of which the scenarios are typically “written” by research teams often consulting prognostics, trend extrapolation and modelling³⁹.

More recently, the technology assessment community has begun to frame the scenario method as a communicative process and an instrument to foster societal involvement in the debate about possible futures⁴⁰. However, few practical examples exist. At the beginning of the 1990s the European Commission developed the “European Awareness Scenarios Workshop” in Denmark and ran this project in different European cities as part of the implementation of Agenda 21 initiatives. Important topics were inner city rejuvenation and city ecology⁴¹. An important element of this approach is the informal involvement of societal actors in decisions about local futures. This shift enabled the use of the scenario method as a participatory technique.

In contrast to other participatory techniques, such as, for example, planning cells and mediation techniques, scenario processes are not aimed at gauging informed judgements about specific planning options or mediating between controversial interests in open

conflict. This technique focuses more on developing common visions for possible futures on the basis of which to derive options for strategic action. Compared to the future conferences and workshops that were developed in the 1960s, the scenario method employs highly structured and systematic processes.

A wealth of different scenario-approaches exists involving qualitative or quantitative data, experts, stakeholders or key decision-makers and following an anticipatory or exploratory route⁴². Yet at a fundamental structural level, most share some common elements:

insert figure 1 about here

Note that the scenario panel will not usually involve the general public and that the actual scenarios are constructed by the research team following careful analysis of brainstorming and deliberations.

This paper reports on an attempt to develop the scenario method as a means of participatory prognostics – a citizen-based method intensively supported by experts. Helping citizens to construct their own scenarios was seen as a potentially useful tool in the process of creating a wider knowledge base for decision-making processes.

Method

Topic & Participants

The citizen scenario workshop was entitled “The relationship of biomedicine and the economy in the year 2014^c”. The observation that the ongoing commercialisation of biomedicine raises, *inter alia*, ethical questions that society has to reflect and evaluate formed the basis for the process. Rather than directing participants towards a specific set of questions and priorities, the scene was left wide open for substantive determination by the group and participants were encouraged to think freely about developments that they

^c 2014: Begin of the 18th German Parliamentary Period

thought were desirable, undesirable or even scary. The process did not aim to exclude possibilities but fostered the unrestricted exploration of a range of interdependent outcomes. The only boundaries to participants' creativity were established upfront by the topic 'biomedicine and the economy' and a focus on the current German system as a starting point (though within its international context).

All in all, 34 men and women (10 experts; 24 citizens) from different professions and aged 18 – 41 participated in the workshop that took place in Germany (Berlin) in the autumn of 2002. The sampling procedure employed a series of announcements in schools, universities and trade associations as well as a number of distribution lists attached to the work of the European Youth Parliament in order to oversample young people with a political interest and an above average education^d. From the self-selected total sample, 24 participants were selected so as to give a balanced distribution with respect to gender, age and occupation.

Insert figure 2 about here

We recognise that this clientele is by no means representative of the wider population. Yet it represents a group of people that take a particular interest in the subject matter and for whom the futures developed in the process are of actual relevance. This was seen as beneficial during the infancy stage of this tool's development. Nevertheless, this kind of theoretical sampling has to be acknowledged as a limitation to which further work in this area needs to pay attention.

Though scenarios do not necessarily have to be "realistic", developing ideas from an incorrect or misunderstood factual basis is neither helpful nor a satisfying process. In order not to confront and possibly confuse participants with too much information upfront,

^d All participants had at least finished high school with many currently enrolled in college programmes.

participants were sent basic information on biomedical developments, their societal relevance and current economic importance. Further factual information was provided by a range of experts^e from relevant fields that were present in the sessions. This set-up worked well as participants initially focused on their own understanding of the topic and only consulted external knowledge to answer specific questions that emerged as relevant from the discussions. Surprisingly, consultation of experts as experts was fairly limited. Instead, they were rapidly included in the discussions on the basis of their personal views rather than as experts delivering specific information.

Structured in seven stages, the entire process lasted seven days and was conducted on three different weekends in two main sessions and one subsection meeting. Participants were paid expenses only.

Stage sequence

The stages were developed from work by Reibnitz⁴³ and are illustrated in figure 3 below.

insert figure 3 about here

Stages:

1. Impact analysis

In a first step, all those factors were identified that were seen as impacting on the role of the economy in biomedical research. In a series of working groups focusing on politics, law, science, society and the economy, impact factors were collected before participants debated and structured them in a plenary session. In order to ensure a common understanding of the terminology, a short description of the status quo of each factor was worked

^e Experts were recruited from Universities covering biology, medicine, economics, social science and ethics.

up. As not all factors were seen as equally relevant and influential, a weighting at this stage led to the selection of 27 relevant factors.

2. Interdependence analysis:

These 27 factors were not perceived as independent of each other. Hence in order to gauge the participants' understanding of these interdependencies, all factors were assessed with regards to their impact in a pair-wise comparison conducted using a cross-impact-matrix. Using a three point scale (0=no influence; 1=little influence; 2=major influence), each participant assessed each factor in combination with every other factor and the other way around, e.g. what is the impact of the acceptance of biomedical products on the freedom of research and *vice versa*. A majority vote dictated the overall group verdict where consensus building through deliberation failed.

3. Grid System (subgroup of five participants)

Once the different impact levels were assessed for each factor using the cross-impact-matrix, they could be placed on a grid system according to their active and passive impact, i.e. to what extent does a single factor impact on elements of its environment and to what extent is the same factor influenced by others? Those factors with high active impact levels were chosen to form the building blocks for the scenario development. Twelve key factors were selected.

4. Projections

Depending on the development of these factors and their interactions, one can imagine different paths toward a future. These possible projections were developed and described by the participants in detail on the basis of an in-depth discussion. Key impact factors and their projections formed the basis for the scenario development.

5. Clustering of Alternatives

In order to develop internally coherent and plausible scenarios, the projections were intercorrelated in a process derived from the use of morphologic tables. That is, projections were assessed in pairs in order to judge whether, in future, they would reinforce or mutually exclude each other or not influence each other to any significant extent. Clusters of projections began to emerge. Some projections featured in more than one cluster. In all, four distinct clusters or scenarios were developed that differed primarily with respect to the “extent of public participation” and “attitude towards progress”. The scenarios “progress first”, “scepticism first”, “profit first” and “participation first” were described in detail by one subgroup each.

6. Analysis of implications

These scenarios describe different frames of reference for the commercialisation of biomedicine. The focus of the analysis of implications was on the kind of consequences that would result from the realisation of these frames. After a process of identifying possible consequences in a group discussion, each participant was given the chance to identify his or her main positive and negative aspects as a means of evaluating their relative importance. Subgroups derived the relevant risks and opportunities in more detail.

7. Recommendations

The recommendations were aimed at policy. Considering the risks and opportunities for *each* specific scenario, participants worked up a number of measures that should be included in policies today in order to foster and realise opportunities while minimizing or avoiding risks. Recommendations were specified with respect to desirable targets and necessary measures. Overall recommendations were not developed due to time constraints. Yet,

depending on the difference between the scenarios, this might be a sensible step in order to gauge overall priorities and worries.

Evaluation

In order to conduct a process evaluation^{44,45}, a questionnaire was administered to all participants at the end of each working session in order to gauge participant satisfaction and create the ability to adjust the process in real time (closed questions on a 5-point Likert scale). This was supported through a series of in-depth interviews during and after the meetings in order to elicit information on opinions towards method, content, organisation and facilitation^f.

Results

Scenarios

Figure 4 below illustrates the twelve key factors identified after the initial three stages arranged on a grid according to their active and passive impact.

insert figure 4 about here

These factors formed the basis for projections which, in turn, could be clustered into four scenarios. Table 1 summarises the factors, their main projections and how they fitted into the scenarios.

insert Table 1 about here

From this detail, four participant subgroups developed the actual scenarios. We would like to stress here, that the research team deliberately did not interfere with the writing of the

^f Interviews were conducted and analysed by Alexander Görsdorf as part of the empirical work for his ethnographic Magister thesis (submitted).

final versions in order to arrive at a text as close as possible to participants' views including the use of their own language. This is a key difference to standard scenario procedures. Though the research team felt the temptation to revise the final output, the main aim, to restructure the scenario method to become a tool for public involvement, remained paramount⁹.

Therefore, the following results represent the core of the original thoughts of the group rather than an analysis on the basis of any particular theoretical framework. Each scenario was worked up as a description of the possible state of affairs including key targets (2014) and recommendations (now). We present here a translated summary of the original scenario descriptions as well as a list of the key targets for each scenario.

Scenario I: Progress first

The current political system is the "expertocracy", i.e. the natural sciences, supported by industry and politics, play the key role in decision-making processes. The permissive legal framework allows research to proceed almost uninhibited, which makes novel medical cures and the individually requested optimisation of the human body possible. Scientific breakthroughs and new applications create a positive climate on the job market. Genetic testing and the establishment of therapeutic possibilities lead to a devaluation of the status of the ill and handicapped. Risk assessments are insufficient and the "generation contract" (the basis of the German pension system) has collapsed. A sidelining of the social and human sciences within the public discussion and decision-making processes encourages the system to proceed further in the same direction.

Key Targets (2014):

1. The ability to deal responsibly with new technological possibilities in the biomedical field should be retained and fostered.

⁹ The original text (in German) can be found at www.bioethik-diskurs.de.

2. A balance between natural and social/human sciences should be struck in order to retain and/or start a critical dialogue.
3. Acceptance of the ill and handicapped should be preserved and supported.
4. Retention of the data protection act and the right not to know.
5. Independent biomedical research should be further supported, albeit with a recognition of the importance of a disparity transfer between the federal states of Germany (the “Länder”).

Recommendations (now):

1. Compulsory risk assessments should receive guaranteed funding within a legal framework that strictly applies the causation principle (German equivalent of the polluter pays principle).
2. The natural and social/human sciences should be on equal footing in terms of funding for research and teaching as well as staffing of expert commissions.
3. Equitable policies should be supported and heavily publicised. The integration of those concerned in decision-making processes should be ensured.
4. Legislation has to determine what kind of data can be used for which purposes and by whom. No-one should be forced to undergo genetic testing against their will.
5. Public funding should be particularly encouraged in areas of societal desirability that are neglected by industry.

Scenario II: Scepticism first

The public and political acceptance for basic and applied biomedical research has been lost within a generally sceptical and distanced Germany. Public funding is administered according to moral and ethical criteria and the subsequent risk-conscious approach prohibits a successful commercialisation through industry and science. Industry is confronted with three options: (1) Adaptation with a focus on conventional and alternative medicine. (2) Moving abroad with grave economic consequences for Germany. (3) Shifting the current regulatory framework through lobbying.

Key targets (2014):

1. Optimisation of the conditions for establishing conventional and alternative medicine in Germany.
2. The move of research and industry abroad has to be avoided.
3. The preconditions for public debate and opinion formation have to be improved.

Recommendations (now):

1. Public funding should support a suitable framework including fundamental research, a pro-research societal climate, tax cuts and incentives.
2. A broad public debate should attempt to replace a diffuse antipathy towards biomedicine with a clear determination of the aspects that are not wanted in order to create room for action.
3. Support for interest in schools, critical reflection in higher education and training, high quality science journalism, transparency in research and a common dialogue.

Scenario III: Profit first

Within an industrial dictatorship, profit, demand and market interests as opposed to politics and society determine targets for research and therapies. Consequently, applications that are not strictly economically viable are dropped and increasing competition undermines the free exchange of research findings not only via patenting. Progress is driven forward without second thoughts so that pre-implantation diagnostics, gene therapy and cloning have succeeded in eliminating hereditary diseases. Positive economic growth leads to an intake of international specialists and an increase in the pace of development. The health system has been privatised efficiently and personal income determines cover. Industrial funding for higher education leads to early specialisation.

Key targets (2014):

1. Economic growth within the biomedical sector.
2. Avoidance of the privatisation of knowledge and an (inter)nationally inequitable distribution of biomedical costs and benefits.

Recommendations (now):

1. Create suitable framework conditions for companies in the biomedical sector.
2. Biomedical research as well as the production and distribution of therapies should be coordinated and supported at an international level.

Scenario IV: Participation first

An increase and improvement in the possibilities for participation in political and economic decisions has led to a growth in public awareness and knowledge as well as improved judgement capabilities. The guiding principles that have come to the fore are the 'sanctity of life', the 'right not to know' and the 'minimisation of suffering'. On this basis and with continuing involvement of citizens, research funding is administered by the state. Under these conditions, industry can invest in alternative and conventional medicine, migrate or conceive of the difficulties as an opportunity. Particular the third option carries the danger that discourses might be manipulated and decisions individualised, neither of which are necessarily socially desirable or sustainable.

Key targets (2014):

1. Secure, effective and binding discourse including industry.
2. A demand-led biomedical production should be supported via an efficient co-ordination of research using public funding directly for research but also as seed-corn money.
3. Social security, justice and an adequate standard of living have to form the basic pillars of the welfare state.
4. The migration of the biomedical sector has to be avoided.

Recommendations (now):

1. Participatory and supervisory processes should be worked up that create a commitment to transparency via ethical certification (such as a consumer organisation seal of approval).

2. A central role for the social/human sciences in a reform of the education and (leadership) training structures and contents should lead to a stronger focus on core values in schools, politics and the corporate sector.
3. The state (research) and industry (application) should share the burden of conducting compulsory technology assessments.
4. Research funding should partly be diverted into a diversity in the alternative medical sector.

Evaluation

Outcome

Within the European context, the Centre for Research on Innovation and Competition in Manchester, UK⁴⁶, and the European Environment Agency⁴² have developed similar scenarios. Further, the World Business Council for Sustainable Development presented biotechnology scenarios³⁴ and its findings from a stakeholder dialogue on intellectual property rights in biotechnology and health care⁴⁷. These reports are not directly comparable as they focus on slightly different topics and use variants of the scenario approach. Nevertheless, they offer a possibility to contextualise the current citizen scenarios.

It is clear from the outset, that experts and stakeholders are able to produce outlooks in far greater detail using a wealth of technical expertise that will always be beyond any group selected from the general public. Intimate knowledge of key factors such as market volume and dynamics, product pipelines and their associated costs and benefits, the way different products and platform technologies are able to generate value in different sectors of the industry as well as insights into the political detail of regulatory and legislative processes, is extremely valuable and out of reach for most non-professionals.

Yet the basic understanding of the way biotechnology might develop in the next decade or so does not differ fundamentally. Though in less detail, economic, political, scientific-technical and public opinion aspects were all dealt with in the citizen workshops presented

in this paper. Whether this lack of detail makes these findings a valuable resource in an expert sense of the word remains a moot point. The participants were well aware that they could not offer the specific information generated by experts in the field. They were also aware, however, that they could contribute something else – a broader view of the societal relevance of biotechnology in the context of their own lives.

The results also showed that the systematic approach of the scenario method led to more profound results than a purely open and unstructured discussion would typically have achieved. This allowed for the derivation of options for action that were specifically matched with the different future opportunities and risks.

Process

The analysis of the evaluation questionnaires confirms this positive impression. The majority of people agreed that the process had been a valuable experience. The averaged results below indicate the level of satisfaction with the method *per se*. Further data on the process itself such as venue, facilitation etc. is not presented in this context.

Insert Table 2 process evaluation data about here

Note the lack of support for the method's rigorous application on which the research team insisted to create a methodological baseline from which to begin to develop sensible modifications. While the systematic nature of the entire process was valued, participants made absolutely clear that the lengthy procedure and the arduousness of the core stages were challenging and left room for improvement. Though the systematic approach was appreciated, many participants voiced their concern about a lack of time given the cognitive tasks they were expected to perform. The long duration of the entire procedure was seen as demanding.

The in-depth interviews revealed that the degree of dissatisfaction may have had less to do with the process itself as more with the organisation and running of the event. It

appeared that participants were somewhat shocked by the complexity of the process that was not sufficiently explained to them at the start of the first meeting. An evaluation of their comments suggests that ensuring that everyone knows exactly what this method involves and why certain steps are included is vital to reduce cognitive load and dissatisfaction. The time demands of the entire process will depend on the intellectual ability and motivation of the group.

A dissatisfaction with the 'interdependence analysis' as revealed by the interview data raises conceptual questions. Similar to a multi-criteria decision analysis, the cross-impact-matrix is an attempt to evaluate participants' views on the basis of their individual components without actively considering the bigger picture. As a consequence, participants may arrive at a different set of priorities than a more holistic approach may have delivered. The research team considered this step useful to encourage participants to reflect their own position. With hindsight, the considerable cognitive and time demands of this stage might have been more of a hindrance than an addition, particularly if one considers a less well educated group of participants. Limiting the number of factors that are entered in the matrix appears to be a preferable option.

This evaluation indicates that the direct transfer of a stage sequence, that proved useful in an expert context, onto a group of "lay" participants is not straightforward. Allowing for enough time to give people a chance to familiarise themselves with and contemplate each step, while, at the same time, keeping the entire procedure transparent, focused and within an acceptable overall time limit seems the most important aspect from a participant's point of view. One way of squaring these conflicting demands may be to select more specific topics in order to reduce the overall scope of the exercise.

On the other hand, it is easy to lose the creative mode of thinking when focusing on too much detail and sticking too closely to procedure. We felt that the real value of this exercise was in exploring the views, understandings and visions of citizens stimulated by social interaction and expert consultation. Some structure certainly helps people to get to

grips with the subject matter and forces them to engage with a broader range of issues and views than they would otherwise deal with. Yet maximising the trade-off between somewhat superficial creativity and exploration on the one hand, and detailed work in an imposed structure on the other, remains a difficult challenge. The specific balance will depend to a large extent on the kind of people sampled.

We felt that a group of many more than 20 people was probably too large to maintain interest throughout the stages. Particular when sampling from a population less well educated, a smaller group size of about 12-15 might be more appropriate in order to ensure comfortable participation during the different stages.

Discussion

The validity of the output as well as the process itself should not only be judged against its level of detail or its technical insight. These are expert based criteria that are only partly applicable to a citizen-expert forum, which ought to be as much about mutual social learning as it is about an insightful debate with an informative output.

Apart from the usefulness of the scenarios, we see some of the exercise's real value in its potential to create surprises and stimulate further and broader debate in public as well as policy circles. We were positively surprised by the complexity of the debate. The fact that more than thirty relevant issues were raised in the brainstorming and that those could be reduced to twelve key impact factors in a difficult process shows once more that non-experts are capable of a more detailed and thoughtful contribution than they are often given credit for⁴⁸. From this perspective, we argue that the process has added value to the existing debate on biomedicine.

It also demonstrates that the issue of biomedicine and the economy cannot be judged outside a broader societal context. Issues that matter to people, such as education, health and the stigmatisation of disease and disability, are as much part of the rich picture developed by the participants as the value of a growing economy, the treatment of painful

and often life-threatening illness or the importance of the corporate sector in a functioning society.

It is important to note that this broader view of the issue is not *caused* by a lack of detailed knowledge in the relevant aspects in a narrow sense of the word. Instead, it *explains* why many people are often dissatisfied with the specific focus of expert-led debates and their outputs. For many it is not about questioning the value of the ability of experts to detach a single topic from its societal context and assess the minute and important detail. Rather, it is argued that the expert assessment is only one way, if an important one, to view the subject matter. Its reintegration into a broader context, as defined by those concerned, is equally relevant and deserves significant attention.

Conclusions

Overall, the process has been a valuable experience for the participants as well as for the experts and the research team. The social learning process encountered over the three sessions was remarkable. Though the citizen-expert-interaction needs to be supported and takes time to develop, the final outcome is evidence that participants responded well to this kind of opportunity.

Within the limitations indicated above, the structure of the scenario method supports a well-founded discussion that builds on participants' initial knowledge and understanding, develops through social interaction and is able to draw on scientific-technical expertise without allowing this particular angle to take over from the original focus. Compared to less focused interactive methods such as conventional focus groups, the scenario method fosters in-depth debate at the expense of open creativity. This has to be kept in mind when using this approach at different stages of decision-making processes.

On part of the participants, the format requires a good deal of time, attentive capacity and concentration as well as communicative ability and willingness to engage. Such high task performance requirements may be interpreted as being prohibitive for a use of the tool with

participants of certain intellectual abilities and motivations. On the other hand, interaction with peers leads to a very varied learning environment that might be successful in drawing less inclined or able people into the process. Further research will have to investigate different structures with different participants in order to optimise the procedure for a particular set of circumstances.

We are confident in recommending that, after a period of methodological optimisation, this approach can be integrated into relevant expert-based activities at policy level such as horizon scanning or future search conferences. This way, a broad set of public views could be included in political debates right from the start – a step that could only help to reduce conflict during later stages and implementation.



Figure 1 Schematic of generic scenario method

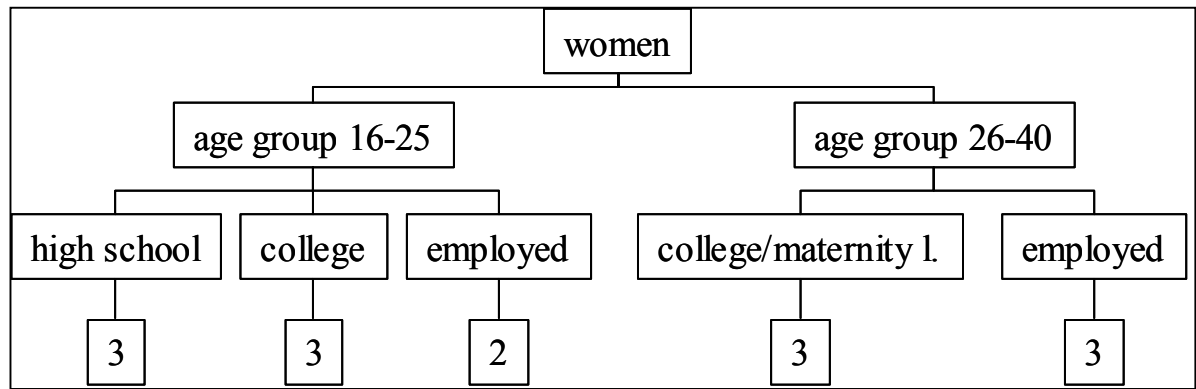


Figure 2 Socio-demographic sample selection criteria for women (approx. eq. for men)

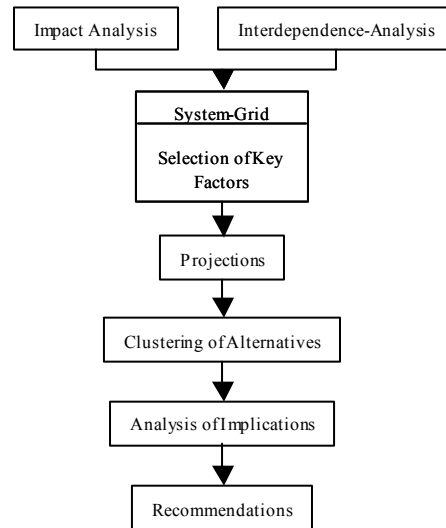


Figure 3 Schematic of the scenario method

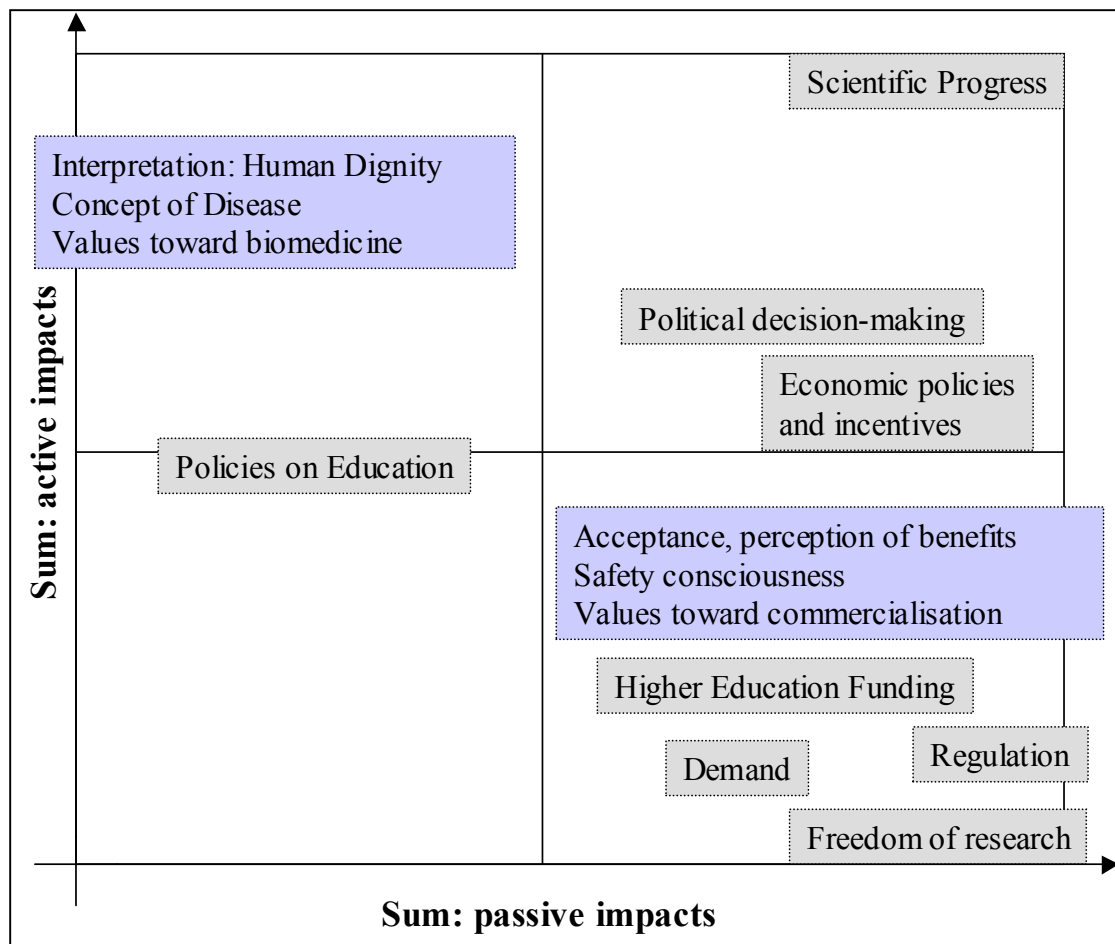


Figure 4 Impact factors positioned on the system grid

Table 1 Key Factors and their interpretation within the different scenarios

	Progress First	Scepticism First		Profit First	Participation First
Scientific Progress	Links with international research			Links with international research (Innovation & Globalisation)	Cost reduction via preventive medicine
	Optimisation of man				
	Changes in society				
Freedom of research	Industry determines content	Prohibition of research on the human genome		Industry determines content	Research regulated via direct democratic elements
	"Everything goes" – zero regulation			"Everything goes" – zero regulation	
Political decision-making	"Expertocracy"	Polit-oligarchy		Economic dictatorship	Direct Democracy
Values toward biomedicine	Treatment of untreatable illness and disease			Treatment of untreatable illness and disease	Treatment of untreatable illness and disease
Interpretation of human dignity	Identity question	Holiness of life			Holiness of life
					Right not to know ^h
Health regulation				Privately financed health service	National regulation and financing of the health service
				Preventive direction	Preventive direction
				Curative direction	Curative direction
University funding	Third party funding	Low budget		Industry funding – large budget	Public funding
Economic policy	Acceleration of progress (state is economically dependent)	Public funding according to moral-ethical criteria		State is economically dependent and retreats	Public funding according to moral-ethical criteria
Education		Alternative school concepts (e.g. Waldorf) for everyone		Privatisation and early specialisation	Broad general education
Demand		Desire: Yes Acceptance: No Funding: Yes	Desire: Yes Acceptance: No Funding: No		
Acceptance	Russian Roulette	Moral dilemma ; all for nothing		Russian Roulette and flippancy	flippancy
Concept of Illness and Disease	Elevation of Health; stigmatisation of illness; data protection			Stigmatisation and data protection	

^h The concept of informational self-determination is prominent in the German bioethical debate, particularly in the context of genetic counselling and compulsory genetic testing for insurance purposes. 'Right not to know' means that a person should not be forced to know something about him- or herself. It is heavily contested as the counter argument (a person has a responsibility to know about oneself in order to protect, e.g. family members) perhaps carries equal weight.

Table 2 Process evaluation data based on a questionnaire administered after the last event

[n=21] 5 Point Likert Scale 1=strongly disagree - 3=neutral - 5= strongly agree	% (std.dev.)
Overall I think the event has been a success.	3.5 (0.4)
The scenario method stimulates new thoughts.	3.6 (0.7)
The scenario method fosters systematic thinking.	3.6 (0.6)
The scenario method is suitable for "lay" people.	3.5 (0.5)
I enjoyed the work.	3.7 (0.7)
The scenario method makes it easier to recognise connections and interdependencies.	3.7 (0.6)
The structured and sequential approach of the scenario method is an advantage.	3.3 (1.1)
If you stray from the original structure of the scenario method, it will tell in the quality of the output.	2.5 (0.7)
Proceeding according to the scenario method can only be seen as a guideline. In order to get decent results, deviations from the standard procedure have to be tolerated.	4.1 (0.4)

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